The Challenge of Stigma

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Speech

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My topic for today can best be described as "Some thoughts on mental illness stigma, particularly as it applies to those mentally ill, how it acts as a barrier to treatment, and why it is such a difficult issue to address". Personal experience, reading and reflecting are the basis of my own thoughts on this subject.

However, let me begin by providing a picture of what life is like for some amongst us. It could be a family member, it could be a friend or colleague and indeed it could be me or you or have been me or you before appropriate steps were taken.

Existence is or close to being hellish. The mind is thumping away with negative thoughts and drowning out all other. Humour has gone and hope seems to have gone with it. Sleep is difficult if not impossible without medication. The poet Samuel Taylor Coleridge put it this way in his poem "Dejection":

> A grief without a pang, void, dark and drear, A stifled, drowsy, unimpassioned grief,
> Which finds no natural outlet, no relief,
>
> In word, or sigh or tear.

What we see is clearly a mental illness but it's all going on within the mind and body of the individual himself or herself. They don't seek counsel. They may self-medicate with alcohol or drugs but in ways harmful to themselves and others.

They survive; indeed, many still work doing their best to cover up the pain within - that "Nightmare Life-in-Death" as Coleridge describes it in his "Rime of the Ancient Mariner". It's grim - and so grim for some they take their own lives. "I'm sorry", they say, "I just can't cope". You may recognise those words as those of Julian Leeser's father written just before his suicide - and about which Julian spoke so movingly in his Maiden Speech to the Parliament[1].

The tragedy in all of this is that we now know that we are speaking of an illness for which remedies are available - not perfect for all but effective for many, and indeed most. Canadian psychologist Mamta Gautam[2] who works with professionals in this space reminds us that sixty to seventy per cent of patients with depression will respond to initial treatment with mono-drug therapy (usually twelve to twenty sessions, or about twelve weeks). Of the thirty per cent who do not respond to initial treatment, the majority will improve on an alternative approach, and upward of ninety per cent will eventually recover fully. It's true of course that depression is just

[1] See Sydney Morning Herald 14 September 2016 for a full transcript of his speech.
[2] http://www.drgautam.com/gautam/article6.html

one of nearly 200 identified mental illnesses but even in relation to those progress has been made and continues to be courtesy of research. There are reasons for hope but....

The problem is that in not talking about their feelings and condition the sufferer is compounding the problem - the more the concealment the more the problem. This self-stigma as we've come to call it can be as "devastating, disabling and life- threatening" as the illness itself:

Self-stigma occurs when an individual internalises negative cultural stereotypes and comes to feel that they are of no value to anyone. This leads to treatment avoidance, a reduction in hope, self-esteem, self-efficacy, empowerment, morale, poor recovery, and lowered quality of life. Self-stigma has been associated with increased symptom severity, and diminished social functioning, insight, and poor recovery[3].

It's this question of stigma I wish to address today. It is, I believe, a much harder nut to crack than we think.

The usual starting point is a discussion of stereotyping, prejudice and discrimination in other contexts but all underpinned by the concept of human equality and human rights. Take your pick for a reference - the Parable of the Good Samaritan in the Bible or perhaps the Universal Declaration of Human Rights agreed upon in the aftermath of World War Two.

Here we go behind the categories from race, gender and sexuality through to class, religion and nationality and warn against the bias and discrimination that can emerge from stereotyping and prejudice. We still argue amongst each other about what genuine respect and compassion for the other means in the real world of difference and inequality and progress can be agonisingly slow for those who are the victims of prejudice but we do have a conscience and ethical building-blocks to assist us along the way. In the final analysis we all share a common humanity even though it is sliced and diced in myriad ways.

What about differences related to our mental well-being? How do we incorporate those into a human rights setting? The World Health Organisation put it this way in their 1948 definition: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". The implication is clear - we should promote mental well-being as well as tackle mental illness. In many ways it is the second- tackling mental illness - that should be given priority. Indeed, the greatest fact holding us back from achieving the greatest happiness for the greatest number is the existence and persistence of many forms of treatable mental illness. Such an aspiration should be part and parcel not only of any nation's health agenda but also of their legislative and policy agendas more generally considered. Take for example the current debate about same-sex marriage and what pressures the negative attitudes of some have on the self-esteem of others. Communities and their governments are players in the mental health space and as such need to recognize and meet their obligations. I'm reminded of research conducted at the University of Columbia that found that for lesbian, gay and bisexual youth the risk of attempting suicide was 20% greater in unsupportive environments than in supportive environments[4].

[3] eather Stuart, Julio Arboleda-Florez and Norman Sartorius, Paradigms lost: Fighting Stigma and the Lessons Learned, 2012, p.8
[4] Mark Hatzenbuehler, "The Social Environment and Suicide attempts in Lesbian, Gay and Bisexual Youth", Pediatrics, May 2011, Volume 127/Issue 5.

Finding a single word - the equivalent of racism and sexism - to replace the more cumbersome "stigma for people with a mental illness" or "mental illness stigma" has been the objective of some clinicians and commentators[5] keen to take up the battle of ideas. Amongst those suggested have been "mentalism", "sanism" and "psychophobia". None of these leap out as immediately obvious descriptors, none anyway that better "mental illness stigma" what it is and that's what it's about.

But back to my suffering individual who feels incapable of seeking help; indeed, who is resisting the very notion. Our political community has said his or her mental health is important to them, perhaps inadequately as there's much to complain about service availability and accessibility particularly but not only in rural and remote Australia. But still the sufferer resists. Perhaps he or she knows from experience that despite the pronouncements from on high others still believe he or she would show weakness by admitting illness and seeking help. More importantly he or she may think disclosure will impact on life chances generally. It's that prejudice thing!

As I noted earlier there's a certain common sense bred of compassion and conscience that leads us to see what is wrong about racism, sexism and homophobia and what is problematical about religiosity, nationalism and class consciousness - it's the very basis for hope in a damaged world. Sparking that compassion is never easy and the problem is compounded in the case of mental illness. It's partly cultural and its part existential.

Deep in our culture is the concept of "freedom of will" not only in respect of what we do but how we feel and think. However, it's one thing to believe in a free society - clearly a good thing - but quite another to assume we are in fact free of influence be it biological, psychological or social. Freedom for the individual is more of a capacity to be developed rather than a given condition. Certainly in respect of mental illness medically supervised interventions, some intensive and some less so, are needed to assist someone better develop their capacity for self-determination. All too often, however, the response to mental illness is simplistic ("just pull yourself together, I've had my ups and downs but have learnt to cope") or naive ("take a few days off and re-charge our batteries"). For lots of us tough love may be appropriate and so too might gentle welfare but not for all, some amongst us may be in the grip of the black dog. It's sometimes persistent and sometimes episodic but whatever, it's different, isolating and excruciating - and it requires medical intervention.

Deep in our condition as human beings we have images of order and chaos, certainty and uncertainty and security and insecurity. Fear is intrinsic to life and keeps us on our toes when it comes to threats to existence. In our everyday life we rely on the "reasonableness, intelligibility and predictability of people we, directly or indirectly, communicate with". Unfortunately, some mental illnesses present themselves as unintelligible, unreasonable or even chaotic. They challenge us and we jump to conclusions about the people in question and indeed about all who have a mental illness, seeing them as either pathetic victims and/or a danger to society. Again what is the case for some becomes the description of all. Such thinking may be understandable

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[5]See Peter Byrne, "Stigma of mental illness and ways of diminishing it", Advances in Psychiatric Treatment, 6(2000) and Iva Cheung, "Sanism and the language of mental illness": http://www.ivacheung.com/2015/5/sanism-and-the- language-of-mental-illness.

but with all stigmas it comes at a cost to those suffering and in need of help. Those of us who see ourselves as in the cool-headed centre of life want them out of sight and out of mind. As

Dusan Kecmanovic [6]puts it these are the deep socio-anthropological roots of mental illness stigma which make it hard to tackle.

What I believe to be happening in today's world is that a continually developing mix of humanism and science has taken us to a better place in respect of the definitions and treatments of mental illness. However, it's proving harder to have this understanding embedded into our culture with its lay and deeply rooted definitions and assumptions about illness, order and freedom. Kecmanovic points to a recent meta- analysis[7] of all studies on mental illness-related beliefs before 31 March 2011 which shows that knowledge about mental illness has increased but it has not been accompanied by social acceptance of persons with mental illness. Too many of us still jump to conclusions before all the evidence is presented. Too many of us still find it hard to accept that being free of negative thoughts doesn't just involve the flicking of a switch.

Stigma, then, is an existential and emotional as well as an intellectual and moral issue. It goes to the heart of things and is a serious hindrance to treatment. Recognizing it and tackling it is a day-to-day challenge for sufferers and non-sufferers alike. To the former we point to the new life that the many therapies may bring. To the latter we point to the human suffering that can and should be avoided, just as we've been doing, if not always successfully, in respect of other forms of prejudice. What we need is not a community that is narve and utopian about mental illnesses some of which will have deep roots in a person's biological make-up and some of which will challenge our assumptions about normality but rather one that understands the complexities of life, how they are problematic for some, how some of us suffer as a result and how treatments can make a world of difference. In particular we should be most concerned about the persistence of high rates of suicide. In other words, we need an educated, caring and compassionate community. We shouldn't pretend it's easy, in fact we ought to assume it isn't, but accept the challenge we must. To know there's a better way creates an obligation to seek that better way.

[6] "The future of psychiatry", Australasian Psychiatry, 20(6), pp. 467-471.
[7] This study is published by G.Schomerus et al in Acta Psychiatrica Scandinavica, volume 125, Issue 6, pp. 440-452.